Stroke services; policy and practice across Europe (book review)

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Published in:
International Journal of Integrated Care

DOI:
10.5334/ijic.72

International Journal of Integrated Care – Vol. 3, 4 February 2003 – ISSN 1568-4156 – http://www.ijic.org/

Book review

Stroke services: policy and practice across Europe

Edited by Charles Wolfe, Christopher McKevitt and Anthony Rudd,
Abingdon: Radcliffe Medical Press, 2002, pp xii, 144,
ISBN 1 85775 4557

If you had to have a stroke, where in Europe would you choose to suffer it? This is the central question in this book on the assessment of stroke services, raised in the final evaluating chapter. Stroke is one of the leading causes of death in contemporary European countries, and often leaves its survivors disabled and dependent on professional and family rehabilitation services and care. Both its incidence and case-fatality have decreased dramatically in the past decades, but evidence from different sources suggests that a plateau phase has been reached. Some authors have argued that the prevalence of stroke has increased dramatically in the elderly, because increased survival enables stroke to repeat itself frequently in the same patient. Further, sharp decreases in stroke incidence or mortality are not very likely to occur and at this current stage, it is appropriate to evaluate the role of health services in shaping epidemiological trends and heterogeneity across European countries. In order to identify possible causes of change in the epidemiology of stroke and to isolate health services within a causal complex affecting population outcomes (including risk factors, stroke severity and stroke management), measurement is the central theme. Measurement involves topics such as mortality certification and coding, aspects of stroke severity and case-mix, and cost-effectiveness. Each of the nine chapters of this book focuses on portions of this central topic of measurement. Most of the authors are associated with the European Union-funded BIOMED programme, and the book's empirical material is hence derived for a substantive part from the BIOMED I and BIOMED II centres. As such, the book is also concerned with the evaluation of what BIOMED has achieved until now and what is still left for further exploration.

Chapter 1 is concerned with the problem of interpreting variations in morbidity and mortality. Based on a review of data (mostly from the WHO-MONICA project) the authors argue that the decline in stroke mortality reflects an improvement in stroke case-fatality rates rather than a decline in the incidence of stroke. Hypertension treatment, metabolic control of diabetes and antithrombotic therapy may have reduced the incidence of stroke but may also have reduced its severity when it occurs. Chapter 2 is about building workable data sets for health services research and offers an overview of domains for questions in BIOMED II. These domains are on patient identification and demography, pre-stroke measurements, time and date of onset, use of resources, stroke severity, discharge destination and functional status at discharge and 3-month follow-up. Chapter 3 is about population disease registers and provides twelve characteristics of a good register. Among the obvious characteristics are quality procedures aimed at completeness, validation and timeliness, clear case definition and active case-ascertainment systems. It is important, but also slightly worrying that the authors add as a further recommendation that ''the register staff should be equally enthusiastic and committed to their work, which requires incentives such as the writing of reports and publication of papers''. Chapter 4 contains a description of variations in the organisation of care using data of the participating BIOMED II centres. Chapter 5 attempts to disentangle the variation in outcomes into differences in the case mix of stroke admissions and differences in the ways in which care is delivered. It provides some evidence for some interventions to have an impact on outcomes among stroke patients. Chapter 6 is on ''institutional performance'', using league tables to rank the BIOMED centres with regard to their mortality and morbidity outcomes. Methods to adjust for case mix are proposed and applied. Chapter 7 focuses on the subjective outcome assessment from the patient's perspective. It describes the variation in subjective outcomes after stroke across Europe and attempts to understand it. Chapter 8 describes methodologies (and their pitfalls) to estimate the cost-effectiveness of stroke care and applies these to the BIOMED stroke programme. Chapter 9 evaluates the positive outcomes of European research and identifies issues that could be tackled in the future.

In our evaluation, we aim to consider what the book has to offer and to whom, what is missing or disappointing, whether the book is well-organised and whether the approaches and methods proposed are amenable to further improvement.

To begin with the merits of the book, we think that it has much to offer when it comes to the introduction of the subject, the description of BIOMED activities and the description of a whole array of problems involved

in conceptualisation and measurement. Throughout its chapters the book offers several key methods, literature and insights that are of value to researchers in the field of health services research. Most chapters are quite meticulous in their efforts to describe the methods used and their many drawbacks. In a certain way, the overall approach is integrative, as it includes many aspects of stroke services in terms of structure, process and outcome. It does not focus on institutional care only, but also attempts to include rehabilitation therapies, family roles, and community services as part of an overall context that may benefit stroke patients. The evaluation of outcomes moreover is not only restricted to mere survival, but also involves health status measurements (mostly using the Barthel Index) at discharge and by 3 months post stroke.

The book does a good job in describing the complexity of quantifying the quality of health care and its role in enhancing probabilities of good outcomes for the patients involved. It seems, however, that in every chapter a struggle is taking place to portray this complexity and to stress that questions like ''whether health services are beneficial in improving stroke outcomes'' or ''why there is variation in subjective outcomes'' remain unanswered. Even with a well-funded and large-scale project it thus appears to be difficult or even impossible to answer the basic questions on the role of health services in the changing epidemiology of stroke. We suggest that the reason so many questions are left unanswered is because the book lacks a sound theoretical perspective. The authors seem so eager to display their measurement skills they forget to recognise that with the observational data used some questions can be answered but others remain matters of dispute, argumentation or even confusion. With the inclusion of a review, or meta-analysis, of trial-investigations, we would have had a better view on the efficacy of particular stroke health services to start with. The final chapter on ''Lessons learned'' contains some of these conceptual notions and could have been placed at the beginning. The last figure of the book for instance provides an excellent insight into the discrepancy between measures of efficacy and community effectiveness. In this figure, the 25% relative risk reduction in bad outcomes established in a meta-analysis of stroke unit trials turns into a community effectiveness of 7% relative risk reduction, after variables like incomplete population coverage and patient adherence have been taken into account. In the absence of new and integral trial research, we simply have to work with data that are generated by this interplay of patient behaviour, disease progression and stroke epidemiology, health care structures and physician's decision-making.

Are the authors successful in dealing with these observational data sources? Although most methods (such as those proposed to adjust for case-mix) seem to work well, we missed a certain feeling for the time-bound nature of the data and the opportunities to compare cohorts with regard to their different outcomes using multivariate logistic regression models or survival analysis. The reason for our discomfort lies partly in a table presented in Chapter 8. In this table, the costs of treating male patients are presented by participating BIOMED centre and separately for survivors and patients who died in hospital. Some centres are found to spend more money on their survivors whereas in other centres the money is allocated to the patients who died. This table clearly raises many questions about case-fatality, the duration of the terminal stage, the balance between lethal and non-lethal outcomes, and the choices made between life and death. Throughout the book we increasingly felt that we lost our touch with the array of patient experiences and physician responses in time that generate the data being studied in the book, much in line with Porter's phrase:

> Patients have roles assigned to them within the scripts of the modern medical drama. Depending upon who is doing the analysis or the accountancy, patients appear as demand, costs and benefits, input or output, voters, clients or consumers of services, bearers of rights or pursuers of litigation, diseased bodies or clinical material, points on a graph or numbers crunched on a software program [2]

Our overall conclusions are that, as far as measurement and description are concerned, there is not much wrong with the book, thereby justifying conclusions drawn in the last chapter that ''data collection is feasible'' and that ''collaboration is stimulating''. But it does not, unfortunately, enhance our understanding of the role health services play in the lives of so many stroke patients, whether that role is beneficial, damaging or largely indifferent. The book is not very specific about the particular services that can be offered during the different stages of stroke and their appraisal and outcomes [3], nor does it offer a clear patient-centric view on integrated care [1]. We know with this book that there are many places to go to if we had to have a stroke, but not which centre has the best performance to serve our needs and why that would be so.

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